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# A qualitative assessment of COPD patients' experiences of pulmonary rehabilitation and guidance by healthcare professionals



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## KEYWORDS

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Health behavior

## Summary

**Background:** The present study aimed to assess COPD patients' experiences during an inpatient pulmonary rehabilitation program and the guidance provided by healthcare professionals. A third aim regarded examining ways to anticipate the transfer to the home environment after completion of the program.

**Abbreviations:** ATS, American Thoracic Society; COPD, Chronic Obstructive Pulmonary Disease; ERS, European Respiratory Society; FEV<sub>1</sub>, Forced Expiratory Volume in the first second; GOLD, Global Initiative for Chronic Obstructive Lung Disease.

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change;  
Healthcare  
professionals'  
counseling strategies;  
Qualitative study

*Methods:* Focus groups and semi-structured interviews were used to collect data from seven COPD patients at the beginning and six other COPD patients at the end of an in-patient pulmonary rehabilitation program, supplemented by a focus group and semi-structured interviews with 14 healthcare professionals of the involved disciplines. Data were analyzed using a phenomenological approach.

*Results:* Starting out, patients displayed trouble with acceptance of their disease, they had insufficient knowledge, and showed difficulties in setting specific realistic goals. Seeing fellow patients struggle with similar problems and tailored counseling by healthcare professionals helped them to overcome these barriers. During rehabilitation, patients became more confident in exercising and managing their daily life activities. Many patients evolved a desire to self-regulate their lives. Incorporating health-enhancing behaviors after returning home into their usual daily routines was anticipated to be tough.

*Conclusion:* Patients undergoing pulmonary rehabilitation experience a complex health behavior change process, in which healthcare professionals fulfill a major contributing role. Therefore, guiding patients through this health behavior change process is a vital component of healthcare professionals' work, regarding which the present study made practical implications such as applying a personalized approach by giving tailored advices, applying an autonomy-supportive counseling style, teaching self-management skills, and referring patients to local exercise facilities.

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## Introduction

Pulmonary rehabilitation is a comprehensive intervention designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence to health-enhancing behaviors [1–6]. Health behavior change is a vital element integrated in many components of pulmonary rehabilitation programs [1]. Initiating and sustaining behavior change is complex, and, accordingly, pulmonary rehabilitation program outcomes may vary due to patient factors and the attitudes and skills of the interdisciplinary pulmonary rehabilitation team [7,8]. For example, pulmonary rehabilitation increased daily physical activity levels in some studies, but not in all [9]. Moreover, benefits of pulmonary rehabilitation decline over time [7,10]. Therefore, there is a need for effective maintenance programs which focus on the implementation of a healthy lifestyle in daily routines, aiming to achieve long-term adherence to health-enhancing behaviors. These findings signify the complexity of health behavior change and warrant further in-depth analyses. Indeed, little is known about the personal and environmental factors that may influence patients' behavior change process during pulmonary rehabilitation. Additionally, being able to develop effective maintenance programs requires greater insight into enablers of behavior maintenance in the transfer from the pulmonary rehabilitation program towards the home environment. Focus groups or in-depth interviews are suitable methods to explore patients' and healthcare professionals' experiences and perspectives during pulmonary rehabilitation. This approach was used before to better understand what should be included in the educational component of pulmonary rehabilitation and how it should be delivered [11]; to better understand the impact of pulmonary rehabilitation on the experience of living with COPD [12]; and to better understand the views and perceptions of COPD patients towards maintaining an active lifestyle after pulmonary rehabilitation [13]. This qualitative study intended to add to the current empirical base a description of

the behavior change guidance provided by healthcare professionals, as well as patients' experiences during the program. The present qualitative study aimed to assess 1) COPD patients' experiences during an in-patient pulmonary rehabilitation program; 2) the guidance provided by healthcare professionals; and 3) ways to anticipate the transfer to the home environment after completion of the pulmonary rehabilitation program.

## Methods

This study applied a descriptive phenomenological approach, and used focus groups, followed by semi-structured interviews, to collect data from patients with COPD at the beginning and at the end of an eight-week inpatient pulmonary rehabilitation program at CIRO+, a center of expertise for chronic organ failure in Horn, the Netherlands [14]. In addition, a focus group and semi-structured interviews with multiple healthcare professionals of the pulmonary rehabilitation team were undertaken.

Following institutional approval, participants were recruited. All eligible patients who were taking part in an in-patient pulmonary rehabilitation program at CIRO+ were subsequently personally invited to participate. Inclusion criteria were a diagnosis of COPD according to GOLD guidelines [15] and sufficient command of Dutch. All personally invited patients were willing to participate, apart from three patients who were too tired or hospitalized. Two other patients were not feeling well enough to participate at the moment the focus group was about to take place. These patients participated in an interview at another point of time. All healthcare professionals working at CIRO+ were eligible to participate in the focus group. Healthcare professionals were randomly invited, and everyone was willing to participate.

All participants completed a questionnaire to provide demographic information about their age, gender, educational level, and – in the case of the patients – marital status,

number of years since the diagnosis of COPD, and the number of previous pulmonary rehabilitation programs they underwent. In accordance with Dutch ethical guidelines, approval by an ethics committee was not required. Participants were informed that all information they provided would be treated confidentially and would only be used anonymously for research purposes. Subsequently, all participants provided written informed consent to take part in the study.

### Focus groups and interviews with patients

Two focus groups were conducted. Group one consisted of four patients who had recently started pulmonary rehabilitation; group two consisted of three other patients who had almost completed the program. In-depth interviews, conducted in May 2010 after the initial focus groups, further explored patients' experiences. Three additional patients who had just started the rehabilitation program were interviewed, as well as three other patients who had nearly completed the pulmonary rehabilitation program. Two researchers (JJMM and CBB) independently established that data saturation had been achieved in the final interviews in both patient groups [16].

### Focus group and interviews with healthcare professionals

One focus group was conducted with seven healthcare professionals at CIRO+. The group included a physiotherapist, an occupational therapist, a physical trainer, a pulmonary physician, a respiratory nurse, a psychologist, and a dietician. This was also followed by in-depth interviews with seven other healthcare professionals with similar professional background.

### The pulmonary rehabilitation program

The eight-week inpatient pulmonary rehabilitation program was in accordance with the latest ATS/ERS Statement on Pulmonary Rehabilitation [1].

### Data collection, interview focus and themes, and data analyses

Two researchers (JJMM and CBB) were present during the focus groups and interviews. All focus groups and interviews were audio-taped and transcribed verbatim. On average, the focus groups lasted 1 h, whereas the interviews lasted 30 min. Topics for the focus groups and interviews were derived from Social Cognitive Theory [17], Theory of Planned Behavior [18], and Self-Determination Theory [19]. Topics focused on patients' attitude regarding physical activity, exercise self-efficacy, motivation, autonomy support by the healthcare professionals, social support by the patients' family and friends, goal setting and outcome expectations. Questions used during the focus groups and interviews are presented in Table 1. Participants were prompted to describe the everyday world as they experienced it. Semi structured focus groups and interviews were conducted asking the participants for descriptions of their

actual experiences (e.g. "Can you describe how you feel about being physically active?") [20]. Dialogues were allowed to evolve naturally and new issues could be raised by the participants.

Qualitative analysis software (NVivo 2.0) was used to facilitate the analysis. Both JJMM and CBB performed a four-step analysis, which was inspired by Giorgi's phenomenological research method [20,21]. We ensured to hold in abeyance any preconceived ideas while listening to, interacting with, and analyzing the stories of the participants [22]. First, the transcripts were read a number of times in order to get an overall impression while we bracketed our preconceptions ('familiarization'). Next, constituting parts known as 'meaning units', which were expressed in the participants' own everyday language, were identified. Third, the meaning units were clustered and coded, and subsequently grouped into especially revealing categories containing more abstract meaning. Fourth, descriptions were prepared based on the contents of the categories and meaning units. These descriptions are presented as results, which reflect important experiences reported by the participants. Finally, the sense of each category was summarized in a single general analysis, which integrated and synthesized the common and essential aspects of the studied phenomenon—referred to as the 'essence' [21,23]. Results were discussed by the two analysts. Since a consensus was not the objective, codes were developed on the basis of interpretations of the interview content, including discrepancies [24]. Back-checking with the interview transcripts ensured that codes were grounded in the primary interview data.

## Results

### Participants

Most patients had severe to very severe COPD, with an age ranging from 54 to 78 years (Table 2). Healthcare professionals' ages ranged between 24 and 52 years.

### Phenomenological analysis

The analytical process yielded several themes, which were condensed into seven overriding categories covering the behavior change process patients go through during pulmonary rehabilitation (Table 3). The content of these categories is abstracted below. The words printed in italics are contextualized words pronounced by the participants and contained in the meaning units. Selected quotations are presented in Table 4.

#### Acceptance

During the first weeks of the rehabilitation program, many patients expressed difficulty coping with the fact that they *could no longer perform daily activities* like housekeeping by themselves the way they were used to. Some patients even had to quit their jobs, because they were no longer able to do their work. For many patients, such dramatic changes in life and their loss of independence were *hard to accept* (Table 4, 1.1). Healthcare professionals noticed that *some patients ignore that they are ill, conceal their symptoms*

from others, or have incorrect perceptions about their physical abilities (1.2). During rehabilitation patients indicated they became more aware of what they were still capable of (instead of what they could no longer do), which favorably affected their acceptance of the disease.

**Goal setting**

Patients entering pulmonary rehabilitation were encouraged to start thinking about personal goals to achieve. A common goal that patients shared was to improve strength and fitness to be able to perform daily activities. The patients' goals were commonly abstract and immeasurable (2.1). Healthcare professionals also indicated that patients often looked back at what they used to be capable of, and desired to recover these physical abilities, which is often an unrealistic perception, and might lead to a sense of failure if their goals are never achieved. According to healthcare professionals, patients often tend to either overestimate or underestimate themselves (1.1; 4.3). Healthcare professionals therefore pointed out that they frequently need to guide patients in formulating specific, measurable and achievable goals (2.2), as well as in stimulating patients to evaluate their goals frequently, and – if necessary – to adjust their goals from time to time.

**Increasing knowledge**

Healthcare professionals indicated that many patients who were just starting rehabilitation do not see the point of changing their lifestyle, or do not realize that they are leading an inactive life (3.2). Healthcare professionals paid attention to giving clear explanations as part of their advice in order to increase patients' knowledge. According to professionals, patients sometimes also had incorrect perceptions about effective strategies to increase their physical activities (3.1). Patients acknowledged that, during rehabilitation, they were learning practical strategies to better cope with their disease and they were finding out about the beneficial effects of exercise on their physical condition.

**Experiencing benefits**

Professionals indicated that, during rehabilitation, patients also experienced how exercise training is beneficial to them (4.4; 4.6; 4.7). Furthermore, patients experienced that they can actually be more physically active, which improved their personal beliefs that they are capable of engaging in physical exercises. Most patients experienced good progress during the rehabilitation process (4.1; 4.2), at times even beyond their own expectations (4.5).

**Table 1** Interview guide.

	Questions
Patients at the beginning of pulmonary rehabilitation	<ul style="list-style-type: none"> <li>- How does COPD affect your daily life?</li> <li>- How do you feel about being physically active?</li> <li>- How have you experienced the rehabilitation program so far?</li> <li>- What are your goals and expectations regarding the rehabilitation?</li> <li>- What is your impression so far regarding the guidance provided at the rehabilitation center?</li> <li>- Do valuable persons in your home environment understand and support you?</li> <li>- What helps/hampers your motivation during rehabilitation?</li> </ul>
Patients at the end of pulmonary rehabilitation	<ul style="list-style-type: none"> <li>- How did you experience the rehabilitation program?</li> <li>- What changes did you notice during rehabilitation?</li> <li>- How do you feel about being physically active? Do you like it? What drives you to be active?</li> <li>- What is your impression regarding the guidance provided at the rehabilitation center?</li> <li>- Have your healthcare professionals offered you choices and options?</li> <li>- Do you feel confident about remaining physically active after completing the rehabilitation program?</li> <li>- What are your goals (concrete plans) and expectations regarding staying physically active after completing the rehabilitation program?</li> <li>- Do valuable persons in your home environment understand and support you?</li> <li>- What helped/hindered your motivation during rehabilitation and have you found a way to cope with these barriers?</li> </ul>
Healthcare professionals	<ul style="list-style-type: none"> <li>- How do you view your role in the behavior change process that patients go through?</li> <li>- What facilitating and impeding factors influence patients in changing their behavior, e.g. becoming more physically active?</li> <li>- How would you describe the way you treat patients? How do you for example try to motivate them? Are you using a specific counseling approach, e.g. Motivational Interviewing?</li> <li>- Do you see patients change during the rehabilitation program?</li> <li>- Do you prepare patients for maintaining the lifestyle changes they made during rehabilitation near the end of the program, and if so, how?</li> <li>- How do you guide patients in setting goals?</li> <li>- Why do some patients do better than others?</li> <li>- Do you also involve the patients' family in the treatment?</li> </ul>

**Table 2** Demographic characteristics of the study population.

	COPD patients (N = 13)	Healthcare professionals (N = 14)
<b>Gender</b>		
Male, N (%)	8 (61.5%)	3 (21.4%)
Female, N (%)	5 (38.5%)	11 (78.6%)
<b>Age (yr)</b>		
Mean (SD)	66.5 (6.9)	33.6 (8.3)
Range	54–78	24–52
<b>Educational level<sup>a</sup></b>		
Low, N (%)	10 (76.9%)	0 (0%)
High, N (%)	3 (23.1%)	14 (100%)
<b>Marital status</b>		
Married or living together with a partner, N (%)	6 (46.2%)	
Divorced/living separately, N (%)	4 (30.8%)	
Widow/widower, N (%)	3 (23.1%)	
<b>Number of years since being diagnosed with COPD</b>		
Mean (SD)	8.9 (6.8)	
Range	3–25	
<b>Number of times participated in a pulmonary rehabilitation program</b>		
Mean (SD)	1.9 (1.5)	
Range	1–6	
<b>Pulmonary function: FEV<sub>1</sub>, %pred.</b>		
Mean (SD)	45.6 (18.8)	
Range	20–57	
<b>GOLD classification of COPD severity:</b>		
GOLD stage I, N (%)	1 (7.7%)	
GOLD stage II, N (%)	3 (23.1%)	
GOLD stage III, N (%)	7 (53.8%)	
GOLD stage IV, N (%)	2 (15.4%)	

FEV<sub>1</sub> = Forced Expiratory Volume in the first second; GOLD = Global Initiative for Chronic Obstructive Lung Disease.  
<sup>a</sup> Low educational level = no education, primary, or lower vocational education; high educational level = secondary vocational education, high school, higher professional education, or university.

**Balancing controlled and autonomous motivation**

Healthcare professionals indicated that many patients entered the rehabilitation program *because their physician had advised them to, or because relatives or friends wanted them to improve their physical condition*. During the first weeks of rehabilitation some patients struggled with the prescribed program and *felt that their freedom had been restricted* (5.1; 5.2), whereas other patients did not express their need for more freedom (5.3; 5.5), because it might have a counterproductive effect (5.4). When talking about the exercise elements of the rehabilitation program, patients just starting out often expressed that they *'have to exercise'* and that they needed someone to urge them to be active (5.3; 5.6; 5.7). During rehabilitation, professionals considered it a challenge to stimulate patients so as to make sure it becomes their own goal to improve, in order to increase the chances of long-term maintenance of their lifestyle changes. By

*providing clear reasons* for the activities incorporated in the rehabilitation program (5.10), by enhancing people's competence (*encouraging them to go on and complimenting them about their achievements*) and by acknowledging patients' own perspectives (*respecting their autonomy and encouraging patients to set their own goals*; 5.16; 5.17), healthcare professionals regularly *see patients' motivation convert* from a controlled type of motivation towards a more autonomous motivation by the end of the rehabilitation program. Some patients – more or less to their own surprise – indicated that they even began to *like exercising* (5.14). However, not all patients ended up being intrinsically motivated. According to most patients *being physically active is a method of staying healthy* (5.8). Healthcare professionals believed that *it is not the professional's goal, a patient should achieve, yet being more physically active should become their own goal* (5.12; 5.15; 5.18; 5.20). This was taken up by patients (5.9). Another aspect of the healthcare professionals' work is to approach each patient differently and thus tailor their communication style to the patient's characteristics (5.19), i.e. when patients appear to vary in the extent of their need for autonomy (5.11; 5.13).

**A feeling of relatedness**

Patients reported that they encounter *trust and support* from their healthcare professionals. Many healthcare professionals carefully listened to the patient, prompted patients to explore their own goals, and enhanced enjoyment, which also encouraged this feeling of relatedness (6.3; 6.4). Besides, patients also encountered support from their fellow patients, with whom they could *share feelings, experiences and advice and encourage each other during exercise training* (6.1; 6.2; 6.10; 6.11). Another important (physically and emotionally) supportive (6.5; 6.6; 6.7; 6.14)

**Table 3** Analytical process.

Meaning units	Categories	Essence
Loss of independence	Acceptance	Process of behavior change during pulmonary rehabilitation
Postponing acceptance		
Acknowledging disease	Goal setting	
Defining achievable goals		
Planning to regularly reflect on progress	Increasing knowledge	
Common lack of knowledge		
Seeing the point of lifestyle changes	Experiencing benefits	
Surprised by own achievement		
Improved self-confidence	Balancing controlled and autonomous motivation	
Shift in motivation		
Encouraged to make own decisions	Feeling of relatedness	
Mutual trust and understanding		
Sympathetic home environment	Transfer to home environment	
Learning self-management skills		
Making concrete plans		

**Table 4** Quotations by categories.

	Quotations
Acceptance	<p>1.1 <b>PB</b>: I just can't accept that I can no longer do many everyday things. It is tough when you realize you can't do things anymore, while you still think you can.</p> <p>1.2 <b>HCP</b>: Patients frequently find it hard to show others that they are ill. They try to function as if they don't suffer from impairments due to their disease. They tend to deny their illness.</p>
Goal-setting	<p>2.1 <b>PB</b>: My goal is to become a little bit better at all the things I do ... become stronger.</p> <p>2.2 <b>HCP</b>: I think it's important that patients set reachable goals. If they don't, they fail, which affects their self-confidence.</p>
Increasing knowledge	<p>3.1 <b>HCP</b>: Patients often have the wrong idea about being physically active. When you ask them about their physical activities, they only think of sports, and forget to take daily activities into account, such as vacuuming, shopping, gardening, etc.</p> <p>3.2 <b>HCP</b>: There are a lot of patients who don't realize that they have an inactive lifestyle. When you discuss their day's schedule with them, they say they do all kinds of things: I use my computer, I often do puzzles, I read a lot... and they're surprised when they become aware that they actually lead a physically inactive life.</p> <p>3.3 <b>HCP</b>: There are great differences in intelligence between patients. Some patients can't make their own choices; they completely rely on others, and are unable to change their own behavior. It's not always the case that they don't want to, sometimes they just can't. They haven't learned to talk about their condition, don't know how to ask for help, etc. You see this relatively often, but on the other hand, there are also patients who are more independent, which makes them better able to change their lifestyle.</p>
Experiencing benefits	<p>4.1 <b>PB</b>: I feel I'm gaining in strength each week.</p> <p>4.2 <b>PE</b>: I've made great progress. I am very pleased with my own performance. I didn't expect that it would go this fast and that I would get so much better.</p> <p>4.3 <b>HCP</b>: During initial assessments, you often hear patients say that they had walked much further than they had expected to be able to. "I haven't walked as much for a whole year as I did today"; and they notice: "Actually, I can do more than I expected to".</p> <p>4.4 <b>HCP</b>: Measurable results are great, but the most important is the feeling patients have about their accomplishments: patients notice that activities at home also become easier to do and that this is actually the result of the rehabilitation program.</p> <p>4.5 <b>HCP</b>: You see patients who are really stunned by their own achievements.</p> <p>4.6 <b>HCP</b>: It is not easy to change a lifestyle you have lived for 60 years. However, when patients see the effect of the exercise training, which gives them a feeling of reward, then they can learn very easily.</p> <p>4.7 <b>HCP</b>: Patients feel their progress not only physically, but mentally as well, it definitely increases their self-confidence.</p>
Balancing controlled and autonomous motivation	<p>5.1 <b>PB</b>: I find it hard that my freedom is restricted, that you just need to follow the program that has been outlined for you.</p> <p>5.2 <b>PE</b>: More freedom to decide what program elements I'd like to do, that's very important to me.</p> <p>5.3 <b>PB</b>: More freedom of choice in the rehabilitation program won't be any good for me. I need the guidance that the professionals are giving. I trust them to tell me what's best for me. I need someone to push me.</p> <p>5.4 <b>PB</b>: I wouldn't prefer to have more choices in the rehabilitation program, like walking instead of cycling. I think I would then tend to choose the easy option.</p> <p>5.5 <b>PE</b>: In my opinion, we're getting enough freedom. The staff always tells us to listen to our body. When your body tells you to stop, you need to stop.</p> <p>5.6 <b>PB</b>: I don't like sports, but I do it because I have to. I don't care for sports. So, I sometimes find it hard to go to training. Then I'm hesitating at home, thinking whether or not to go, but then I convince myself to call the cab and go after all. I see other people struggling with this too, and I try to stimulate them as well.</p> <p>5.7 <b>PE</b>: I think I have to remain active and to keep playing sports.</p> <p>5.8 <b>PB</b>: When I make progress, it's nice to exercise. Personally, I'm more encouraged by the progress, the results, than by the pleasure of the sport itself.</p> <p>5.9 <b>PB</b>: That's what I learn here ... that I'm here to do this for my own benefit, not to please others.</p> <p>5.10 <b>PB</b>: I like to be told about the reason why we need to do all these things. Up to now, I've been given those explanations.</p> <p>5.11 <b>HCP</b>: I think people are different ... some need to be told what to do and even find it pleasant to have control taken over by others, because they can't decide for themselves what to do, whereas others make more deliberate choices for themselves.</p>

*(continued on next page)*

Table 4 (continued)

	Quotations
	5.12 HCP: It's important that <i>they</i> want to change. If people don't want to, then they won't succeed. You sometimes need to accept that patients won't change their behavior if they're not motivated.
	5.13 HCP: Some patients need to be told what to do, in brief and explicit terms, whereas with others I need to talk much more, mostly the higher educated ones. You try to support and motivate everyone, but the approach differs.
	5.14 HCP: Some patients have never played sports before, have never liked it, and will never like it. They will probably quit sports after they've returned home. On the other hand, there are also patients who become aware that, maybe it isn't fun, but since they've experienced the positive effects, they will remain active. They believe exercising is good for their physical condition. And there's also those who actually begin to really like exercising. So it differs a lot and you also see people change along the way.
	5.15 HCP: It makes me feel good when patients have become more independent at the end and their quality of life has improved. You try to create an activity pattern that satisfies the patients themselves.
	5.16 HCP: We try to stimulate patients to take responsibility and make their own decisions. Sometimes they need information to do this. Then we think aloud together with the patient.
	5.17 HCP: When patients come up with their own solutions, it works better than when we think of solutions for them.
	5.18 HCP: My goal is to help patients achieve their own goals.
	5.19 HCP: We try to have regular conversations with patients and evaluate how things are progressing: should we continue the way it's going, should we do more, or less, or in a different way? This way we try to keep the program as personally tailored as possible. It is not static, but a dynamic development, but we always keep in mind that we want to make progress.
	5.20 HCP: It's the patient who's responsible. Together with them, we consider the pros and cons, but in the end they're the one who's made the decision.
	6.1 PB: At times I don't feel like going to the gym, but then I think: well, the others will also be there, so let's go. Afterward we always have a bowl of soup together, which is fun.
	6.2 PB: We're all in the same boat; we all know why we're here. That is stimulating.
	6.3 PB: I feel the rehabilitation professionals understand us and show their sympathy. They're really helpful.
	6.4 PB: The rehabilitation professionals guide you very well. They're attentive, try to motivate you, they make it fun.
	6.5 PB: For my partner, it's hard to see me out of breath and not able to do some things. All I can do is fight it. My children are always there for me too, they're willing to help me with everything.
6.6 PE: If I have a relapse, my wife will always support me ... She really encourages me.	
6.7 PB: Friends are always there for me, they help me work in the garden and tell me to take it easy.	
6.8 PE: They don't understand, someone who doesn't have this shortness of breath can't understand what it's like.	
6.9 PE: ( <i>After a day when the patient's wife accompanied him at the rehabilitation center</i> ) Yes, my wife now understands my condition better, but she doesn't know how to cope with it.	
6.10 HCP: Patients don't feel they're alone. It gives them a feeling of reassurance: "The way I react is not unusual".	
6.11 HCP: Patients receive much support from each other. We've got very practical education sessions, where we ask the patients to work together. We encourage them to ask other patients questions when they see that the others are able to do things they're not.	
6.12 HCP: A disease like COPD doesn't affect only you; your entire family has to cope with the consequences of the disease, especially when they don't understand. Patients also enjoy the contact with fellow rehabilitants, because they can share experiences. In this way, they don't feel alone.	
6.13 HCP: We often hear that others don't understand what's going on. They say you're looking well. When a patient is sitting in a chair, others don't notice anything special about them.	
6.14 HCP: Some patients really need their partner to integrate physical activity in their daily lives. Involving partners in the treatment can be very helpful, when partners identify barriers in the home environment that the patient forgot to mention, and they can also assist in specifying goals for when the patient has returned home.	

A feeling of relatedness

(continued on next page)



Table 4 (continued)

	Quotations
Transfer to home environment	<p>7.1 PE: When patients leave the rehabilitation center, they all receive a list of addresses of sports facilities you could go to. They need to make their own plans, and take action themselves.</p> <p>7.2 PE: It doesn't work at home like it does here at the rehabilitation center. They can't possibly be at the gym from 9 to 3.</p> <p>7.3 PE: I will try to keep up the goals I've now achieved, and to stay at the level I'm now at.</p> <p>7.4 PE: I've registered with a gym; I keep on cycling, gardening, working a couple of hours. I'm not going to sit in a chair.</p> <p>7.5 PE: My goal is to go to the physical therapist twice a week, and train with the same equipment as I'm using here. I'm planning to exercise at 70% of my maximal power.</p> <p>7.6 PE: It'll be hard when I'm back home to grab that bicycle or go to the gym. Remaining motivated will be hard, but it's something you need to try.</p> <p>7.7 PE: At the rehabilitation center you exercise in a group, at home you're alone and you won't tend to do exercises by yourself in your living room.</p> <p>7.8 PE: Back home everything is different. Here at the rehabilitation center, you're busy all day; you can't reach that level back home. You just need to force yourself to be active at regular moments.</p> <p>7.9 PE: You need to find a new rhythm back home. Structure and regularity are important.</p> <p>7.10 PE: I can choose for myself how I want to remain active. I'll do it because I want to.</p> <p>7.11 HCP: It's important that clients recognize exacerbations and know how to cope with them in their home situation. This makes it possible for them to function independently, which can delay hospital admissions.</p> <p>7.12 HCP: During exercise training I try to link the activities here to activities in the home environment. I think the long-term effect of rehabilitation will be lost if we don't link in with their home situation.</p> <p>7.13 HCP: Patients need to take their own responsibility after they get back home. I know that's hard for some people. They don't get as much to do as in our rehabilitation program. It's a period of stabilization and maintenance instead of a constructive period. But some people just can't manage to structure their activities at home. When they have an exacerbation, they're back to square one. Even just when the weather is bad and it snows for 2 days and they can't get out of the house, they immediately lose their rhythm. It's hard for them to start up again after a relapse. They then try to resume their activities immediately at the same level they were at, which is sometimes not feasible, and so they give up. It all has to go without problems; otherwise they have a hard time. You need to be cognitively strong to manage physical activity in your daily life back home.</p> <p>7.14 HCP: It is hard to get yourself to go for walks, and keep it up. Here at the rehabilitation center you get up and go along with the others to the next item on the program. At home, they need to integrate it in their own daily lives. Patients need to arrange that for themselves.</p> <p>7.15 HCP: When patients experience good progress, they don't anticipate pitfalls. Consequently, they're not prepared when they encounter unexpected barriers. They should learn to come up with alternatives. It works best when patients propose their own solutions, instead of us giving them advice on how to cope with barriers.</p> <p>7.16 HCP: I think relapse is mainly due to poor self-management skills.</p>

Note. PB = patient at the beginning of pulmonary rehabilitation; PE = patient at the end of pulmonary rehabilitation; HCP = healthcare professional.

or inhibiting (6.8; 6.9) environment – especially in the longer term – is the patient's home environment. COPD is a disease which has *a great impact on the patient's entire family* (6.12). Patients indicated that sometimes people could not immediately see that they are ill, which may lead to a lack of understanding (6.8; 6.13). It is therefore important that patients learn how to communicate to people in their home environment what they are and aren't capable of doing and explicitly discuss with their family and friends how they can support them.

#### Transfer to the home environment

Near the end of the rehabilitation program, attention needs to focus on the situation at a patient's home to *prepare patients for maintaining their improved physical condition* back home. This is a second phase of goal setting, in which healthcare professionals guide patients towards incorporating exercise in their daily routines, e.g. *by linking rehabilitation elements to similar activities in the home environment* (7.12). A common pitfall concerns patients who believe that they need to be as physically active at

home as they used to be in the rehabilitation program (7.2; 7.8), *which level of activity is infeasible* according to these patients. Near the end of rehabilitation, patients report that they are guided towards returning to their home environment by means of mental preparation – prompting patients to make concrete plans how often and where they will be active after rehabilitation (7.5) -, as well as practical preparation – referral to other healthcare professionals (regular check-up by a pulmonary physician and nurse) and to sports providers or primary healthcare physical therapists (7.1) -. Yet eventually, in the period after rehabilitation *it all comes down to patients' own responsibility and self-regulation* (7.9; 7.10; 7.11). Both patients and professionals indicated that consolidation of the improved physical activity level costs less effort in an environment in which all facilities are available and guidance is present, such as the rehabilitation center (7.7; 7.13; 7.14). In the home environment, on the other hand, patients need to manage their own lifestyle and chronic disease again. Although some patients are able to make more or less concrete plans (7.3; 7.4; 7.5), others are less confident about their ability to sustain their improved physical condition after returning home, *where everything is different* (7.6). *Not everyone feels capable of making this transition successfully by themselves*. Professionals at the end of the rehabilitation trajectory start teaching self-management skills, such as stimulating patients to listen to their body and act upon this, to develop some structure at home, and to anticipate pitfalls. Patients can already start this process during the weekends at home, which gives them the opportunity to talk about their experiences with the healthcare professionals. In order to encourage patients' self-management, healthcare professionals further try to *encourage patients to come up with their own solutions in case they experience barriers* (7.15). Patients indicated that they *need to find a new rhythm at home, in which regularity and discipline are very important values*. Healthcare professionals indicated that it is hard for many patients, *being independent and transferring new habits to their usual daily routines* (7.14; 7.16). Barriers such as exacerbations, or even a few days of poor weather conditions, can push patients out of their rhythm and make it hard for them to get back into it again.

## Essence

The study provided insights into the process of behavior change patients go through during pulmonary rehabilitation. Just starting out, patients displayed trouble with acceptance of their disease. Seeing fellow patients struggle with the same problems and being made aware of their condition by healthcare professionals helped them to overcome their frustrations. Further, patients appeared to have insufficient knowledge about their disease and ways of coping with COPD, and they showed difficulties in setting specific realistic goals. During rehabilitation, patients appeared to have become more confident in exercising and managing their daily life activities. They gained knowledge, acquired new self-management skills and learned how to set achievable goals and make concrete plans how to achieve them. Many patients also evolved a desire to self-

regulate their lives. A tailored counseling approach by the healthcare professionals, as well as support by fellow patients, family and friends appeared to be beneficial to patients. Finally, it became clear that incorporating health-enhancing behaviors after returning home into their usual daily routines was anticipated to be tough.

## Discussion

This is the first study to address issues about personal and environmental factors that may influence patients' behavior change process during pulmonary rehabilitation using a phenomenological approach, including patients with COPD and healthcare professionals. Factors impeding progress during pulmonary rehabilitation appeared to be non-acceptance of having COPD, lack of knowledge and difficulty to set specific goals and self-manage the disease. Factors advancing progress during rehabilitation were found to be support by healthcare professionals and family and friends, shifting towards qualitatively better types of motivation regarding lifestyle changes, acquiring self-management skills, and support in finding (new) suitable daily activities.

## Barriers during pulmonary rehabilitation

The psychologically, physically and socially restrictive nature of COPD can be frustrating for patients and their loved ones, and it takes time for them to accept living with the consequences of COPD [12,25]. This process of disease acceptance seems to evolve naturally during rehabilitation by getting in touch with fellow patients, whereas raising awareness by healthcare professionals helped patients to overcome their frustrations as well. Healthcare professionals concluded that patients who delay the acceptance of their disease consequently postpone the moment when they start to implement changes to improve their lifestyle. Besides, the present study revealed that many patients do not have sufficient knowledge about their condition and do not know how to cope with accompanying impairments when they enter the program, which is in line with previous findings of Jones [26]. Knowledge about COPD is needed in order to set specific, realistic, personal goals during rehabilitation – in order to avoid a sense of failure if goals cannot be achieved -, and to enhance working towards better self-management. Healthcare professionals thus have a critical role in making patients aware of their condition and to guide the acceptance process of having COPD.

## Facilitating factors during pulmonary rehabilitation

The experience of increased self-efficacy during rehabilitation is in line with the findings of other qualitative explorations among patients with COPD [12,13,27,28], as well as the importance of social support by fellow patients and healthcare professionals [29]. This stresses the importance of organizing pulmonary rehabilitation in groups of peers with similar chronic respiratory diseases. Also the involvement of patients' family during pulmonary rehabilitation

seems useful, i.e. by offering them the opportunity to accompany the patient for a day.

Evidence shows that autonomous motivation, as opposed to controlled motivation, is associated with more favorable outcomes (e.g. greater well-being, and greater participation in physical activity in a variety of contexts and greater perseverance [30,31]). Patients' motivation often converted towards a more autonomous motivation near the end of rehabilitation. For most patients being active turned out to be a method of staying healthy; some patients indicated that they even began to like exercising. At first sight, the pulmonary rehabilitation program in itself is rather controlling – patients are 'forced' to follow a prescribed program. Nevertheless, most healthcare professionals appeared successful in providing autonomy support towards patients, thus increasing the chances of positive outcomes.

Autonomy is also linked with the concept of patient empowerment [32]. Autonomous motivation could therefore also help to enable patients with COPD to self-manage their condition. Autonomy should not, however, be confused with independence. When making an autonomous decision, this does not necessarily mean that a patient does not involve others when making choices; one can volitionally choose to be dependent, for instance, on a healthcare professional or a family member. COPD can deplete some patients of their resources to fight it, while some other patients have low natural resources, which results them in a state of helplessness, and can also immobilize them [12]. Although autonomous motivation can be seen as the optimal type of motivation, making a deliberate volitional decision to hand over control can in some cases be an advantageous type of motivation as well. Indeed, this is likely to work out best for patients who i.e. expected that they would tend to take the easy options when left to themselves, or they are just unable to cope with the disease themselves (Table 4; 3.3). These patients can be referred to as 'autonomously dependent' on others [33].

### Transfer from pulmonary rehabilitation to the home environment

As patients leave the rehabilitation program, they are suddenly deprived of a safe and motivating environment [12]. This makes patients vulnerable to relapse into old unhealthy habits. The present study highlights the need for a careful preparation of the patients by healthcare professionals in order to help them to incorporate new lifestyle behaviors in daily routines. In-patient rehabilitation in particular implies a major difference between the rehabilitation period and the resumption of home life. Furthermore, it is an important task of healthcare professionals to contradict false perceptions and make sure that patients understand that their return home is a period of stabilization instead of a constructive period. Long-term maintenance of lifestyle changes made during a pulmonary rehabilitation program is difficult [34]. For example, patients are used to supervised exercise training during pulmonary rehabilitation. During and following pulmonary rehabilitation, patients need to be supported in finding (new) suitable daily activities to perform by themselves.

Healthcare professionals can facilitate long-term maintenance by referring patients to existing local exercise facilities and/or physiotherapists [35]. Additionally, patients should be encouraged to identify (leisure and/or domestic) physical activities that they enjoy doing and for which they feel competent. Monitoring daily activities – for example by keeping a diary – may stimulate patients to continue. Moreover, patients need to come up with their own solutions when encountering problems, such as extra costs (including transportation) to continue exercising, and poor weather conditions. Obviously, exacerbations are a threat for the daily activities in patients with COPD. Therefore, patients need to be able to identify a COPD exacerbation early, know when and where to consult healthcare professionals, and how to resume their normal activities following exacerbation.

### Methodological considerations

Strengths of the current study include the phenomenological approach; the assessment of viewpoints of both patients and healthcare professionals, which supplemented each other; and the timing of the focus groups and interviews (at the start and at the end of the pulmonary rehabilitation). Furthermore, all interviews were conducted by the same researchers, which increased the consistency in data gathering, while coding was performed by two researchers working independently. The current methodology may result in socially desirable answers. However, confidentiality was assured, and participants were very open and even admitted their flaws. Obviously, the current findings are hypothesis-generating rather than definitive, as sample size was limited and pulmonary rehabilitation teams may differ around the world. Therefore, the current findings need to be reproduced in other pulmonary rehabilitation centers.

### Conclusion

To conclude, patients with COPD go through a complex process of health behavior change during pulmonary rehabilitation, in which healthcare professionals fulfill a major contributing role. Therefore, guiding patients through this health behavior change process is a vital component of healthcare professionals' work. A personalized approach by giving tailored advices, applying an autonomy-supportive counseling style, teaching self-management skills, and referring patients to local exercise facilities seem important behavior change enabling counseling strategies.

### Conflict of interest

The authors declare that there are no conflicts of interest.

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## References

- [1] Spruit MA, Singh SJ, Garvey C, et al. An Official American Thoracic Society/European Respiratory Society statement: key concepts and advances in pulmonary rehabilitation – an executive summary. *Am J Res Crit Care Med* 2013;188(8):1011–27.
- [2] Lacasse Y, Martin S, Lasserson TJ, Goldstein RS. Meta-analysis of respiratory rehabilitation in chronic obstructive pulmonary disease: a cochrane systematic review. *Eura Medicophys* 2007;43:475–85.
- [3] Costi S, Crisafulli E, Antoni FD, Beneventi C, Fabbri LM, Clini EM. Effects of unsupported upper extremity exercise training in patients with copd: a randomized clinical trial. *Chest* 2009;136:387–95.
- [4] Harrison SL, Greening NJ, Williams JE, Morgan MD, Steiner MC, Singh SJ. Have we underestimated the efficacy of pulmonary rehabilitation in improving mood? *Respir Med* 2012;106:838–44.
- [5] Pitta F, Troosters T, Probst VS, Langer D, Decramer M, Gosselink R. Are patients with copd more active after pulmonary rehabilitation? *Chest* 2008;134:273–80.
- [6] Scherer YK, Schmieder LE. The effect of a pulmonary rehabilitation program on self-efficacy, perception of dyspnea, and physical endurance. *Heart Lung* 1997;26:15–22.
- [7] Coultas D, McKinley J. Update on pulmonary rehabilitation for COPD. *Clin Pulm Med* 2009;16:183–8.
- [8] Egan C, Deering BM, Blake C, et al. Short term and long term effects of pulmonary rehabilitation on physical activity in COPD. *Respir Med* 2012;106:1671–9.
- [9] Cindy Ng LW, Mackney J, Jenkins S, Hill K. Does exercise training change physical activity in people with COPD? A systematic review and meta-analysis. *Chron Respir Dis* 2012;9:17–26.
- [10] Casaburi R, ZuWallack R. Pulmonary rehabilitation for management of chronic obstructive pulmonary disease. *New Engl J Med* 2009;360:1329–35.
- [11] Wilson JS, O'Neill B, Reilly J, MacMahon J, Bradley JM. Education in pulmonary rehabilitation: the patient's perspective. *Arch Phys Med Rehab* 2007;88:1704–9.
- [12] Toms J, Harrison K. Living with chronic lung disease and the effect of pulmonary rehabilitation: patients' perspectives. *Physiotherapy* 2002;88:605–19.
- [13] Hogg L, Grant A, Garrod R, Fiddler H. People with COPD perceive ongoing, structured and socially supportive exercise opportunities to be important for maintaining an active lifestyle following pulmonary rehabilitation: a qualitative study. *J Physiother* 2012;58:189–95.
- [14] Spruit MA, Vanderhoven-Augustin I, Janssen PP, Wouters EFM. Integration of pulmonary rehabilitation in COPD. *Lancet* 2008;371:12–3.
- [15] Vestbo J, Hurd SS, Agusti AG, et al. Global strategy for the diagnosis, management and prevention of chronic obstructive pulmonary disease, GOLD executive summary. *Am J Respir Crit Care Med* 2013;187(4):347–65.
- [16] Kuper A, Lingard L, Levinson W. Critically appraising qualitative research. *BMJ* 2008;337:a1035.
- [17] Bandura A. *Self-efficacy: the exercise of control*. New York: Freeman; 1997.
- [18] Ajzen I. The theory of planned behavior. *Organ Behav Hum Dec*. 1991;50:179–211.
- [19] Deci EL, Ryan RM. *Intrinsic motivation and self-determination in human behavior*. New York: Plenum Publishing Co; 1985.
- [20] Giorgi A. A phenomenological perspective on certain qualitative research methods. *J Phenomenol Psychol* 1994;25:190–220.
- [21] Polkinghorne DE. Phenomenological research method. In: Valle RS, Halle S, editors. *Existential–phenomenological perspectives in psychology: exploring the breadth of human experience*. New York: Plenum Press; 1989. pp. 41–61.
- [22] Wojnar DM, Swanson KM. Phenomenology an exploration. *J Holist Nurs* 2007;25(3):172–80.
- [23] Midtgaard J, Røssel K, Christensen JF, Uth J, Adamsen L, Rørth M. Demonstration and manifestation of self-determination and illness resistance—a qualitative study of long-term maintenance of physical activity in posttreatment cancer survivors. *Support Care Cancer* 2012;20:1999–2008.
- [24] Patton MQ. Enhancing the quality and credibility of qualitative analysis. *Health Serv Res* 1999;34:1189–208.
- [25] Barnett M. Chronic obstructive pulmonary disease: a phenomenological study of patients' experiences. *J Clin Nurs* 2005;14:805–12.
- [26] Jones D. Too little, too late – the patients' perspective on education for COPD. *Chron Respir Dis* 2007;4:189–90.
- [27] Arnold E, Bruton A, Ellis-Hill C. Adherence to pulmonary rehabilitation: a qualitative study. *Resp Med* 2006;100:1716–23.
- [28] Vincent E, Sewell L, Wagg K, Deacon S, Williams J, Singh S. Measuring a change in self-efficacy following pulmonary rehabilitation: an evaluation of the PRAISE tool. *Chest* 2011;140:1534–9.
- [29] Halding AG, Wahl A, Heggdal K. 'Belonging'. 'Patients' experiences of social relationships during pulmonary rehabilitation. *Disabil Rehabil* 2010;32:1272–80.
- [30] Ng JYY, Ntoumanis N, Thøgersen-Ntoumani C, et al. Self-Determination theory applied to health contexts: a meta-analysis. *Perspect Psychol Sci* 2012;7:325–40.
- [31] Teixeira PJ, Carraça EV, Markland D, Silva MN, Ryan RM. Exercise, physical activity, and self-determination theory: a systematic review. *Int J Behav Nutr Phys Act* 2012;9:78.
- [32] De Ridder D, Depla M, Severens P, Malsch M. Beliefs on coping with illness: a consumer's perspective. *Soc Sci Med* 1997;44:553–9.
- [33] Lynch MF, Vansteenkiste M, Deci EL, Ryan RM. Autonomy as process and outcome: revisiting cultural and practical issues in motivation for counseling. *Couns Psychol* 2011;39(2):286–302.
- [34] Ries AL, Kaplan RM, Myers R, Prewitt LM. Maintenance after pulmonary rehabilitation in chronic lung disease: a randomized trial. *Am J Respir Crit Care Med* 2003;167:880–8.
- [35] Helmink JHM, Meis JJM, de Weerd I, Visser FN, de Vries NK, Kremers SPJ. Development and implementation of a lifestyle intervention to promote physical activity and healthy diet in the Dutch general practice setting: the BeweegKuur programme. *Int J Behav Nutr Phys Act* 2010;7:49.